



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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Published Six Times A Year by The National Ichthyosis Foundation, P.O. Box 252, Belmont, CA 94002. Telephone (415) 591-1653. NIF is a non-profit California corporation, for the benefit and education of its members and the public regarding medical, psychological and social aspects of Ichthyosis, a genetic skin condition. Letters, suggestions and contributions welcome.

***** FROM THE EDITOR'S DESK *****

NEWSLETTER SUPPORT -- We are sorry to lose the wonderful support we have received for the past three years from Hermal Pharmaceutical Laboratories, which arranged for the printing of the **FOCUS** newsletter. The General Manager, Mr. James Tombros, has been a loyal supporter of NIF since its inception, and his dedication and his company's generous commitment to education in dermatology is exemplary. The Foundation could never have afforded to publish such a high quality newsletter for you without the help of Mr. Tombros and his company.

This loss means you and I as NIF members must assume the responsibility and expenses for publishing the newsletter ourselves. The newsletter isn't free, you know. Everyone who receives a copy is expected to contribute to its publication costs. Publishing and mailing the newsletter six times in 1985 is projected to cost almost \$12,000. Where do you think that money will come from? Member response to the last newsletter asking for donations brought in less than \$2,000, far short of the \$30,000 we need to carry on and move forward. Does this mean members don't care if the newsletter continues? It's up to you. Remember, all contributions are tax-deductible!

NATIONAL ACTIVITIES -- 1984 NIF activities focused on December. We held two regional conferences (Washington, D.C. and Tulsa, OK), attended the American Academy of Dermatology ("AAD") annual meetings, and consulted government leaders in Washington, D.C. about increasing Ichthyosis research.

AAD MEETINGS -- The 1984 annual meetings of the AAD in Washington, D.C. were a great success, thanks to the support lay foundations like NIF get from the AAD meeting staff. In recent years, the Academy has been particularly responsive to the needs of the patient support groups who wish to participate in the national meeting. Charles Elchhorn and Mike O'Connor represented NIF in the Exhibit Hall, Medical Presentations, and meetings with AAD officers. Over 5,000 doctors attended the meetings, as well as almost 2,000 pharmaceutical company exhibitors. The doctors' interest in NIF was higher than ever before, and we were cleaned out of every piece of literature we brought!

1984 REGIONAL CONFERENCES -- Although registrations were down because the last newsletter was late, the Washington D.C. and Tulsa, Oklahoma Conferences were both real successes for all who attended. Valerie Lutens, Contributing Editor, reports on the Washington conference in this Newsletter. Look for details on Oklahoma in the next edition. In addition to the doctors who provided the medical presentations, we want to thank Betty McMasters and her crew in the Tulsa Chapter for all their help in making the day such a success.

FUND-RAISING -- We have begun our fund-raising effort to support the newsletter and full-time Executive Director position, and have begun interviewing candidates. These are our primary goals for 1985, and your personal support is the first step. If we help ourselves first, we are in a better position to request donations from business and government. If we don't care ourselves, why should anyone else? Take a look at the list of generous donors in this newsletter. They alone have kept NIF alive for all of us. Thank them in your heart, and then join their ranks with a check. Remember, it's deductible!

BOARD OF DIRECTORS POSITIONS -- The terms of some members of the NIF Board of Directors are expiring, and new qualified and enthusiastic replacements are sought to take the Foundation into its new growth stage. Please write or call with your nominations.

FIRST COMPUTER SURVEY -- Because the last newsletter was delayed, many members missed the deadline for returning the computer survey. THE DEADLINE HAS BEEN EXTENDED TO MARCH 1, 1985. Please return your survey forms. An extra copy is attached. Make photocopies, if necessary. Your participation is essential to the success of the project. The results can lead to increased research and funding, as well as specific treatments for Ichthyosis. Your survey information can make a real contribution. Please do your part!

NEW ICHTHYOSIS TYPES -- Any skin disorder with a thickened keratin layer that is dry and scaling is collectively lumped under the title "Ichthyosis". Did you know that dogs and mice have forms of Ichthyosis? Some doctors from England have recently identified an unusual form in people in the West Indies. Although we usually think of Ichthyosis in four major categories, there are actually many subclassifications, some extremely rare. The common thread is dry, scaling skin, but the causes and symptoms can vary dramatically.

CONFERENCE VIDEOTAPES -- The medical presentations for the 1983 National Conference in Chicago have been transcribed and are being reviewed by the Medical Advisory Board speakers for accuracy. It's tough to turn a speech into a written article. We hope to publish excerpts in coming issues of **FOCUS**. Presentations from the 1984 Regional Conference in Washington were video-taped. We hope to make these tapes available soon to all members on a rental basis for nominal fees.

THANK YOU, DONORS -- It's been a long time since the NIF Board has taken the time (and space) to thank the people whose faith, hope and charity have kept the Foundation going for all of us. These are the people who took a giant step for everyone with Ichthyosis. We are grateful for every contribution, of service as well as money, and want to mention some of our most generous supporters here:

Dr. Raymond Caputo
Ortho Pharmaceutical
Joseph and Linda Menzla
Dr. Eugene Van Scott
Jim Griffin
William Geismann
Jeannette Jensen
Ken and Marge Boyd
Dr. Peter Elias

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Kenneth and Marlene Morris
Betty McMasters
Preceptor Beta Rho
Dr. Lowell Goldsmith

If we misspelled your name or failed to include you, please accept our apology and sincere thanks. We haven't forgotten you. You are the heart and blood of our organization.

***** MEDICAL FOCUS *****

TELL ME DOCTOR COLUMN -- Look for it in the next issue of FOCUS, but send in your questions right away!

NEW!! HOT TIPS COLUMN -- A new feature of the newsletter will be practical tips we get from all over: members, doctors, other publications, and common sense. Neither the National Ichthyosis Foundation nor its Medical Advisory Board recommends any "Tip." NIF acts only as a clearinghouse for information about Ichthyosis. You should consult your own physician and follow their advice before acting on any Tip. A Tip that's good for one person may be fatal for another.

SCALES IN HAIR: How to get them out? It's the most common question we get. Dr. Gene Van Scott of our Medical Advisory Board recommends applying a scale softening lotion or cream to the scalp and covering it with a shower cap overnight. A morning shampoo, massage and brushing does the trick for most patients.

DEODORANTS: Body odor caused by perspiration is a problem for most people, even many with Ichthyosis. Anti-perspirants may block what little perspiration there is. Consider a deodorant spray **without** an anti-perspirant in it. Check the label before you buy. More on odor problems next month. Got any suggestions?

SAUNA SUITS: Many dermatologists recommend their patients use a waterproof exercise suit to cover their topical treatment overnight for better occlusion. (I use one over my 50% water/50% propylene glycol solution.) Unfortunately, most of these suits are made of relatively stiff and cold vinyl plastic. Although inexpensive to start with, they don't last through very many washings. Worse, they are downright uncomfortable. Good News: The **Sleep Sauna Co.** at 404 Westview Road, Elkins Park, PA 19177 offers a soft and comfortable waterproof **Sleep Sauna** suit developed by dermatologists. Easy to wash, it's made from a soft woven nylon that should last for years instead of weeks. They cost under \$40 and are a real value in comfort and durability.

THE WINTER BLUES: Most people know that winter air is drier, indoors and out. Don't forget that people (children, especially) with Ichthyosis tend to feel cold (and heat) more than people with normal skin. If you can't move to Hawaii or another warm, humid climate for the winter, at least remain aware of your child's needs. It's hard to calculate the right amount of clothing, because too much is almost as bad as too little. If the child is old enough to answer, just ask! And don't forget school classroom conditions, winter as well as summer.

GLYCOLIC ACID: Some members have been reporting considerable success with preparations using glycolic acid, the member of the alpha hydroxy group with the smallest molecule. It helps break apart the clumped skin cells so they can be washed off. Patients report that it's hard to find. Herald Pharmacal, Inc., of Richmond, VA has a line of glycolic acid products, including **Aqua Glycolic Lotion**, a 5% preparation. Tell your doctor and pharmacist.

PALM AND SOLES: An adult member with EH that causes her palms and soles to be thick and hard offers this suggestion to others with her problem: Apply a softening cream to hands or feet for several minutes, then shave the "extra" skin off with a regular shaving razor. Proceed with Caution!!

NATURAL OR SYNTHETIC?: Natural fibers, such as cotton or wool, may be nice, but they tend to wick moisture from the body, thereby actually aggravating Ichthyosis. Consider less absorbent synthetics next to the skin.

Got any Hot Tips? Please share them with all of us. Write to the Editor, ICHTHYOSIS FOCUS, PO Box 252, Belmont, CA 94002. Thanks!

COMPUTER DATA INPUT SHEET - SURVEY ONE

NEW DEADLINE: MARCH 1, 1985

This information will be used only by NIF. None of the following information will be made available at any time to any person or organization without your prior written permission.

Note: Please complete one questionnaire for each individual with Ichthyosis. If you need more forms, either photocopy this one, or call or write to NIF. We need to have a separate, completed questionnaire for every person with Ichthyosis, so mention the survey to family, friends, and acquaintances.

Patient name _____ Today's Date _____

Street Address _____

City _____ State _____ ZIP _____

Date of birth _____ Place of birth _____

Present Marital status: Single ___ Sep ___ Div ___ Widowed ___ Children? Yes ___ No ___

Children with Ichthyosis? Yes ___ No ___ How many? _____ (Survey for each one, please!)

Number of doctors you have seen regarding Ichthyosis: _____ Non-"M.D." doctors? _____

What type of Ichthyosis? Lamellar? _____ Vulgaris? _____ X-Linked? _____

Epidermolytic Hyperkeratosis? _____ Other? _____

If "Other", please explain: _____

When was your case first diagnosed? (Age) _____ Was the diagnosis correct the first time? _____

When was your case last reviewed and/or diagnosed? Month _____ Year _____ New diagnosis? _____

Present/last doctor _____

Address _____

City _____ State _____ ZIP _____

Current treatment and frequency _____

On a scale of 1 to 10 (1=poor, 10=Excellent), rate the success of your present treatment: _____

Past unsuccessful treatments? Describe: _____

Is your Ichthyosis condition constant? Yes ___ Changes seasonally ___ Changes with locations ___

Does it cause physical pain? Always ___ Often ___ Sometimes ___ Never ___ Typical Degree? 1-10 _____

Does it cause emotional pain? Always ___ Often ___ Sometimes ___ Never ___ Typical Degree 1-10 _____

Do you have any other chronic illnesses? _____

Any other body parts affected? (Nails, hair, etc. - Please list) _____

Do you know that Ichthyosis is an incurable genetic defect? _____

Do you know that some kinds of Ichthyosis can be inherited? Knew _____ Didn't Know _____

Do you know if your Ichthyosis can be inherited? Know ___ Don't know ___ Can be ___ Can't be ___

Learned about NIF from Doctor ___ Other medical Person ___ Member ___ TV ___ Magazine ___ Other ___

How many other living people with Ichthyosis have you met? (number) _____

Your Relatives, living or deceased, with Ichthyosis:

<u>Name</u>	<u>Relationship</u>	<u>Age</u>	<u>Type of Ichthyosis</u>	<u>State</u>
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Other information that didn't fit above? _____

COMMENTS: _____

PLEASE MAIL TO: NIF COMPUTER SURVEY, PO BOX 252, BELMONT, CA 94002

